Mortality among People Receiving Developmental Services in Vermont FY 2003

Introduction

Every year the Division of Developmental Services publishes a report on the number of people who died during the past year while receiving developmental services. An analysis of individual deaths and also of trends in mortality is a component of health and safety oversight for a publicly funded developmental services system. The purpose of the report is to provide information about trends, and keep watch for indicators that could help us prevent certain types of death or illness in the future.

Death in and of itself is not an indication that something has gone wrong. If we offer lifelong supports to people, they will eventually die while receiving developmental services. Offering care to people who are terminally ill and supporting them to feel safe and cared for while they are in the dying process is an important part of developmental services.

In Vermont, the low number of people who die each year makes it difficult to detect trends, and to be confident in their statistical significance even when detected. It is important to looks at trends over several years, and to look at data from other states when possible.

The Numbers

In FY 2003, 40 people receiving Developmental Services died. The total number of deaths of people receiving Developmental Services over the past six years is as follows:

Deaths of People Receiving Developmental Services

	Deaths	Total # in DS Services
FY 2003	40	2889
FY 2002	37	2795
FY 2001	36	2702
FY 2000	25	2560
FY 1999	30	2387
FY 1998	23	2285

Type of Living Situation of People who Died in FY 2003

Nursing home	9
Group home (DS operated)	1
Other residential care home	2
Shared living/developmental home	18
Respite/developmental home	1
Independent/apartment	3
Natural family	6

Note that the residence of a person does not necessarily indicate the location where a person died (*e.g.,* a person may have lived in a group home, but died in a hospital). Two individuals had lived in residential care homes before moving to a nursing home for their final illness; we counted their residence as the residential care home. Similarly, one individual passed away during a temporary residence in a nursing home; we counted her long-term residence, which was a developmental home.

Some people with developmental disabilities who live in nursing homes receive DS-funded supports through the PASARR program; others don't want or need them. In FY 2003 there were 9 deaths among nursing home residents who received PASARR supports, and 3 deaths among nursing home residents with DD who didn't get any DS funded services. Only the 9 who received or were waiting for DS-funded services are counted in this report.

In 2001, 26.4% of all Vermont deaths occurred in a nursing home (42.6% were in hospitals, and 22.5% were at home). With 12 of 40 deaths of Vermonters who received DS-funded services occurring in nursing homes, the rate of placement in a nursing home for a final illness (30%) was higher for people with DD than for the Vermont population as a whole. In FY 03 the Developmental Services system's ability to serve people through final illness in non-institutional settings was not as strong as the systems that served all Vermonters. This figures bears watching in future years to see whether it is a trend, or a temporary aberration.

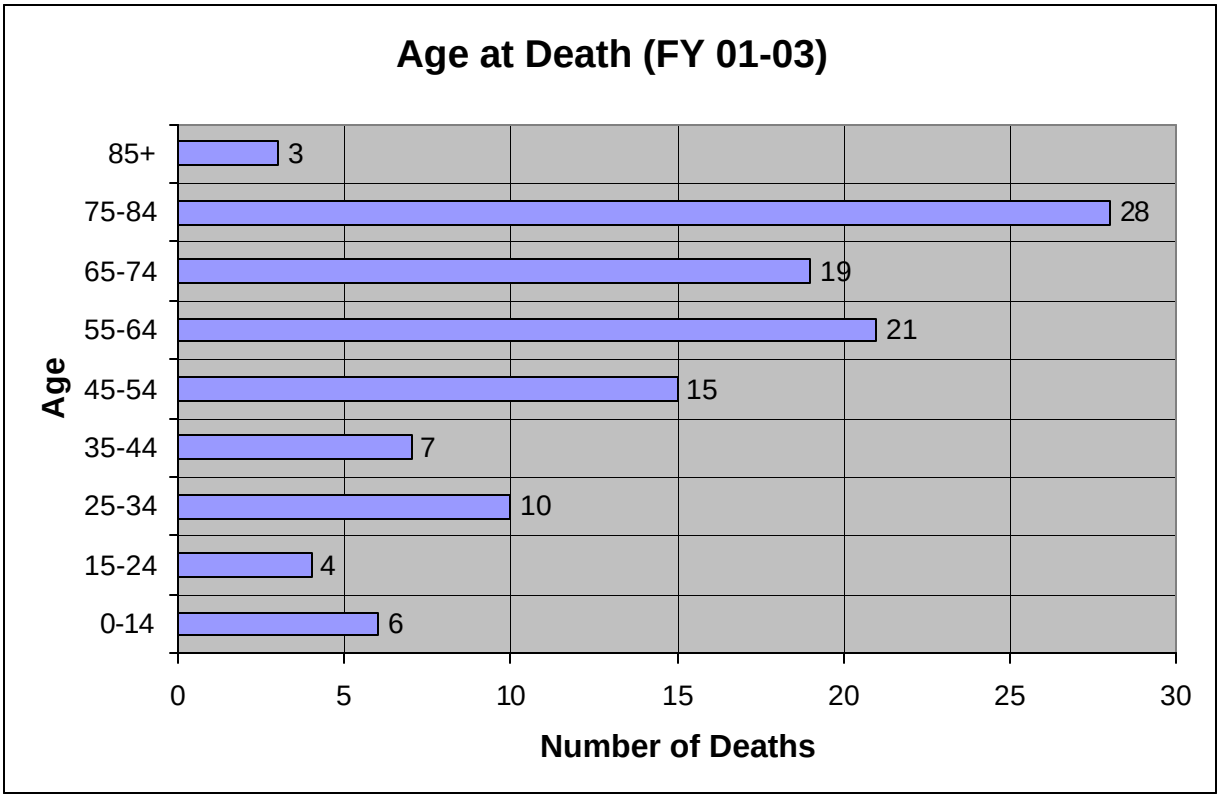
As in previous years, more people died who were being served in shared living/developmental homes than in any other type of residence. This does not indicate that developmental homes are more dangerous than other types of supports. In Vermont's developmental services system, shared living/developmental homes are the most prevalent type of residential support outside the natural family.[1]

[1] In FY 03, 911 people lived in developmental/hared living homes.

Here is the age at death of people receiving developmental services this year and last year.

Age at Death for People in Developmental Services in FY 2002 and 2003

Age	No. of Deaths in FY 2002	No. of Deaths in FY 2003
0-14	2	2
15-24	1	1
25-34	4	3
35-44	0	2
45-54	6	4
55-64	4	10
65-74	9	5
75-84	10	12
85+	1	1
Total	**37**	**40**
Median	**67**	**62**
Mean	**59**	**60**



The *median*[2] age of death for people who received DS-funded services in FY 2003 was 62. This is considerably higher than the median age of death in FY 2001, which was 56, but quite a bit lower than the median age of death in FY 2002, which was 67. The *average (mean*[3]*)* age of death for people who died in developmental services in FY 2003 was 60, as compared with a *mean* age of death in FY 2002 of 59.

In contrast, 61% of all Vermonters who died in 2001 were 75 or older.

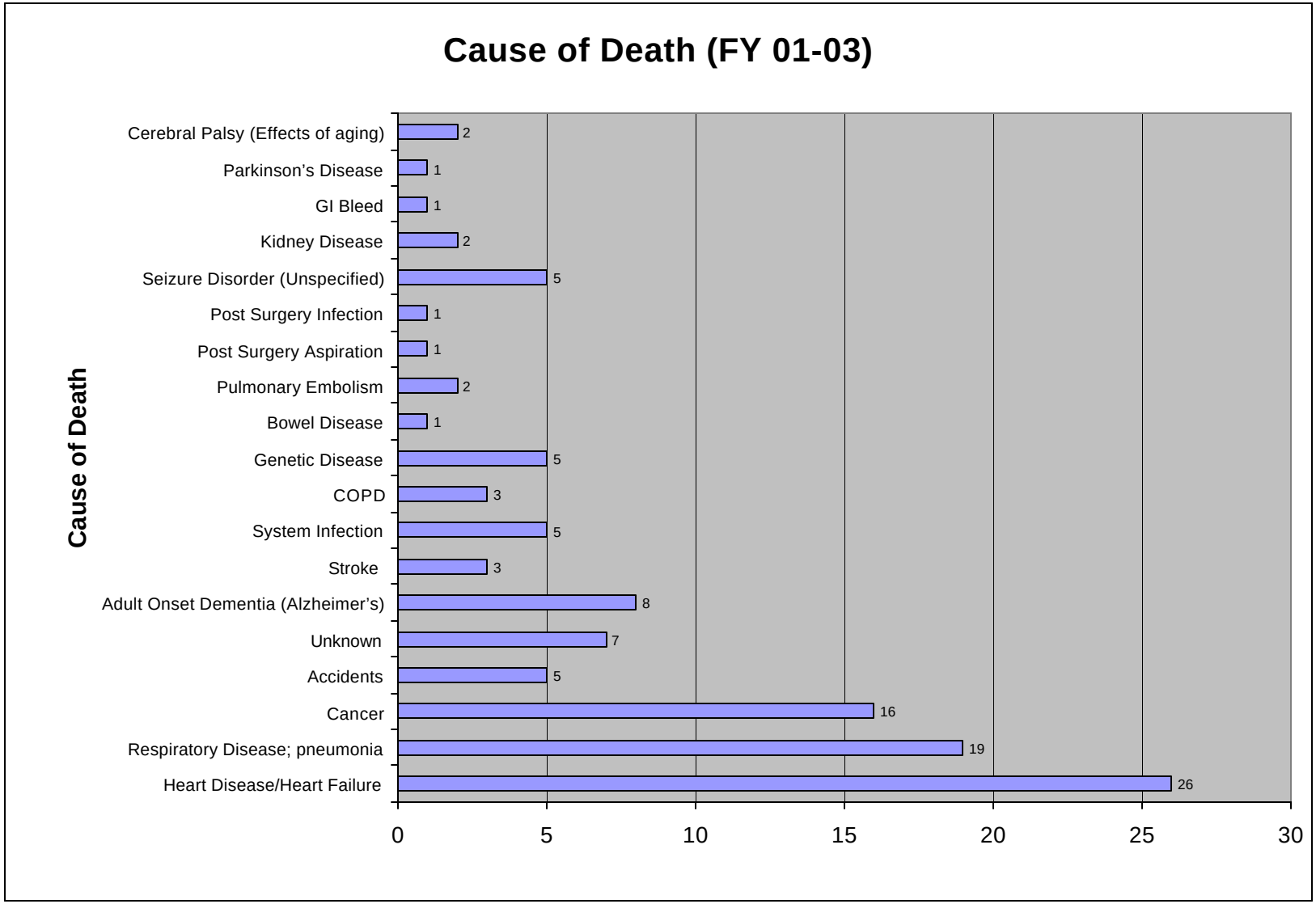
Cause of Death

Cause of death for people who received developmental services and died in FY 2001-3 was as follows:

Cause of Death for People in DS

	FY 01	FY 02	FY 03
Heart Disease/Heart Failure	7	5	14
Respiratory Disease; pneumonia	6	7	6
Cancer	4	7	5
Accidents	1	3	1
Unknown	3	2	2
Adult Onset Dementia (Alzheimer's)	5	2	1
Stroke	1	2	0
System Infection	3	2	0
COPD	0	2	1
Genetic Disease	4	1	0
Bowel Disease	0	1	0
Pulmonary Embolism	0	1	1
Post Surgery Aspiration	0	1	0
Post Surgery Infection	0	0	1
Seizure Disorder (Unspecified)	0	1	4
Kidney Disease	1	0	1
GI Bleed	1	0	0
Parkinson's Disease	0	0	1
Cerebral Palsy (Effects of aging)	0	0	2
Total	36	37	40

[2] *Median* means that half the people who died were older than this age, and half were younger.
[3] The *average* or *mean* is the sum of the age at death for everyone divided by the number of deaths.


Cause of Death (FY 01-03)
Cause of Death
Cerebral Palsy (Effects of aging)
Parkinson's Disease
GI Bleed
Kidney Disease
Seizure Disorder (Unspecified)
Post Surgery Infection
Post Surgery Aspiration
Pulmonary Embolism
Bowel Disease
Genetic Disease
COPD
System Infection
Stroke
Adult Onset Dementia (Alzheimer's)
Unknown
Accidents
Cancer
Respiratory Disease; pneumonia
Heart Disease/Heart Failure
2
1
1
2
5
1
1
2
1
5
3
5
3
8
7
5
16
19
26
0
5
10
15
20
25
30

Where there was a known underlying disease process (such as cancer) we listed that, rather than the immediate cause (such as pneumonia). At present, we choose a single cause of death for each person. Many people had several conditions which contributed to their failing death, and the choice of a single primary cause of death is sometimes rather arbitrary. For instance, diabetes was a contributing cause of death for some people, but it is not listed as the primary cause of death for anyone on this list.

Pneumonia is particularly difficult to classify. Where a person had another active disease process such as cancer or Alzheimer's (and we knew about it), which caused the person to be in frail health, we would pick the other process, even though the person may have had pneumonia at the end. Where a person had health problems which had caused weakened health, such as a genetic disease, but had not been considered to be terminally ill, we generally identify pneumonia. Several people died suddenly, and their death was attributed by the physician who filled out the death certificate as cardiac arrest or some other heart condition, but this diagnosis was not verified by autopsy. Some of these deaths may have been due to stroke or other sudden event, but we have no way of knowing this. Some people had been in failing health as the result of multiple health problems, and the cause of their finally slipping away was attributed either to a respiratory or heart condition, when both played a part.

It is possible that some of the respiratory or cardiac deaths would have been more accurately classified as chronic lower pulmonary disease, which is the 4th leading cause of death among all Vermonters, yet does not appear as a frequent cause of death in this report. Our reporters may not be familiar with this disease.

Two persons are classified as "unknown" cause of death:

A 25-year-old woman who lived with her aunt. and died in her sleep

A 38-year-old man who lived alone and was found dead in his home

In some cases an autopsy might have clarified the cause of death but was not wanted by the family, or else DDS was notified of the death too late for there to be an autopsy.

In FY 02 we saw a spike in cancer – related deaths, including a possible trend of increased cancers related to smoking. That trend did not continue this year. The number of cancer deaths decreased from last year. There were no cases of lung cancer, and no trend among the types of cancer (1 brain, 1 pancreas, 1 colon, 1 uterine, 1 unknown). Two of five individuals who died from cancer had been smokers. In Vermont, cancer is the second leading cause of death. We have no way of counting the number of people with DS-funded services who were successfully treated for cancer, but we have anecdotal knowledge that there are many such people.

We are also collecting information to identify whether a person had Down's related dementia (Alzheimer's), as the progression of this disease in people with developmental disabilities follows some unique patterns. In the past year, two people passed away with Down's-related Alzheimer's. Since there are starting to be national data on this type of Alzheimer's disease, we will be able to look at how our figures compare with national data. (Note that the two individuals who died with Down's related Alzheimer's in FY 2003 died at ages 46 and 70 respectively.)

For all Vermonters in 2001 (the most recent year for which these numbers are available) the leading causes of death were (in the following order):

1. Heart disease
2. Cancer
3. Stroke
4. Chronic lower pulmonary disease (also called COPD)
5. Accidents (unintentional injuries)
6. Diabetes
7. Alzheimer's (includes other forms of dementia)
8. Influenza; Pneumonia
9. Kidney diseases
10. Suicide

In general, these have stayed steady as the leading causes of death. Cancer deaths continue to increase in the state, as do deaths from chronic lower pulmonary disease (previously known as "chronic obstructive respiratory disease"). Just a few years ago Alzheimer's was the 10th leading cause of death; it has steadily risen to its present position as the 7th leading cause of death. Heart disease and stroke, while still major killers, have decreased dramatically in their total numbers.

Medico/legal death

No one who received developmental services died in FY 2003 from suicide, homicide, or other weapons-related cause.

Accidental death

Only one death was classified as accidental in FY '03. It occurred as the aftermath of devastating injuries from a fall which had occurred 11 months earlier.

Prevention

Vermonters with developmental disabilities generally die from the same causes as other Vermonters, and the same prevention activities which are effective for

all Vermonters can reduce mortality among people with developmental disabilities.

Smoking, obesity, and lack of physical activity continue to be prevalent among people with developmental disabilities. Concerted efforts at smoking cessation, weight-reduction, and opportunities for physical activity can make a tangible difference in extending the lives of Vermonters with developmental disabilities.

The identification of a primary physician and cancer screening can reduce mortality and are tracked by the Department of Health as part of their Healthy Vermonters 2010 program.[4] In these two areas, people who receive developmental services rank well.

On-going monitoring

Better understanding of the proximate and underlying causes of death continues to be a tool for prevention. Prompt notification of every death is key to this process. Prompt reporting of deaths makes possible timely screening to determine whether to seek an autopsy or investigation of care surrounding death. In several cases one to several days elapsed before DDS was notified of the death. In most of these cases, the delay occurred because the individual lived with family and the family did not notify the agency of the death.

The Division of Developmental Services actively seeks an autopsy in any death where the death was unexpected and the cause of death is not clearly established. The Medical Examiner initiates an autopsy where there is a possibility that the death did not occur from natural causes. Approximately 10% of all Vermont deaths are investigated by autopsy. The rate of autopsy among DS-funded individuals was about the same (5 of 40). A recent survey found that the rate of autopsies for individuals in developmental services programs is about 11%.[5] In some cases where we would have liked to have an autopsy, it was not possible because of late reporting or because of natural family objection.

Any death report which raises a concern that abuse or neglect of care may have occurred is reported to Adult Protective Services (for adults) and SRS (for children. To our knowledge, no deaths of DS-funded individuals were reported to APS or SRS in FY 03.

[4] Access to a primary care physician is Objective No. One of Healthy Vermonters 2010, and regular screening for colorectal, breast and cervical cancer are also primary objectives. In FY 2000 94% of adult Vermont women had had a Pap smear within the past 3 years, and 78% had had a mammogram within the past 2 years.

[5] The Columbus Organization. Mortality Review Survey: Survey of the States. Submitted to the California Department of Developmental Services. May, 2002.